

Recovery, Empowerment and Self Determination: A Vision for the future of Public Mental Health Systems

Commission on Mental Health Law Reform
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Commissioner
DMHMRSAS

Chronic and Serious Mental Illness

- Psychosis:
 - “break or disconnection from reality”
- Schizophrenia (literally “split mind” – but not split personality)
 - Delusions
 - Hallucinations
 - Disorganized speech
 - Grossly disorganized or catatonic behavior
 - Negative symptoms
 - Types
 - » Paranoid
 - » Disorganized
 - » Catatonic

What is Recovery?

- Patricia Deegan, Ph.D.
- *Recovery: The Lived Experience of Rehabilitation* Psychosocial Rehab Journal (1988)

What is Recovery?

- ✿ Current Notion dates back to mid-1980's
 - Harding's (1987) Vermont Longitudinal Study that showed the course of severe mental illness was NOT inevitable deterioration.
 - Several first person accounts of “recovery”
 - ◆ Deegan (1988)
 - ◆ Fisher (1992)
 - ◆ Copeland (1994)

Harding et al. Study

- Sample size: 269
- Average length of follow-up: 32 years
- Rates of significant improvement or recovery for schizophrenia:
✓ **62-68%**

Harding, C.M., Brooks, G.W., Ashikaga, T., Strauss, J.S., & Breier, A. (1987). The Vermont longitudinal study of persons with severe mental illness: I. methodology, study, sample, and overall status 32 years later. American Journal of Psychiatry, 144(6), 718-726.

Harding, C.M., Brooks, G.W., Ashikaa, T., Strauss, J.S., & Breier, A. (1987). The Vermont longitudinal study: II. Long-term outcome of subjects who retrospectively met the criteria for DSM-III schizophrenia. American Journal of Psychiatry, 144(6), 727-735.

(From Deegan' Lessons in Recovery and Resilience)

Harding et al. 1987 Study

- Recovery defined as four criteria:
 - Having a social life similar to others in the wider community
 - Holding a paying job or volunteering
 - Being symptom free
 - Being off of psychiatric medications
- 62% of people diagnosed with schizophrenia met 3 of the 4 criteria

(From Deegan' Lessons in Recovery and Resilience)

Tsuang et al. Study

- Sample size: 186
- Average length of follow-up: 35 years
- Rates of significant improvement or recovery for schizophrenia:
✓ 46%

Tsuang, M.T., Woolson, R.F., & Fleming, J.A. (1979). Long-term outcome of major psychoses: 1. Schizophrenia and affective disorders compared with psychiatrically symptom-free surgical conditions. Archives of General Psychiatry, 36, 1295-1301.

(From Deegan' Lessons in Recovery and Resilience)

Ogawa et al. Study

- Sample size: 140
- Average length of follow-up: 22.5 years
- Rates of significant improvement or recovery for schizophrenia:
✓ 57%

Ogawa, K, Miya, M., Watarai, A., Nakazawa, M., Yuasa, S. & Utena, H. (1987). A long-term follow-up study of schizophrenia in Japan with special reference to the course of social adjustment. British Journal of Psychiatry, 151, 758-765.

(From Deegan' Lessons in Recovery and Resilience)

DeSisto et al. 1995

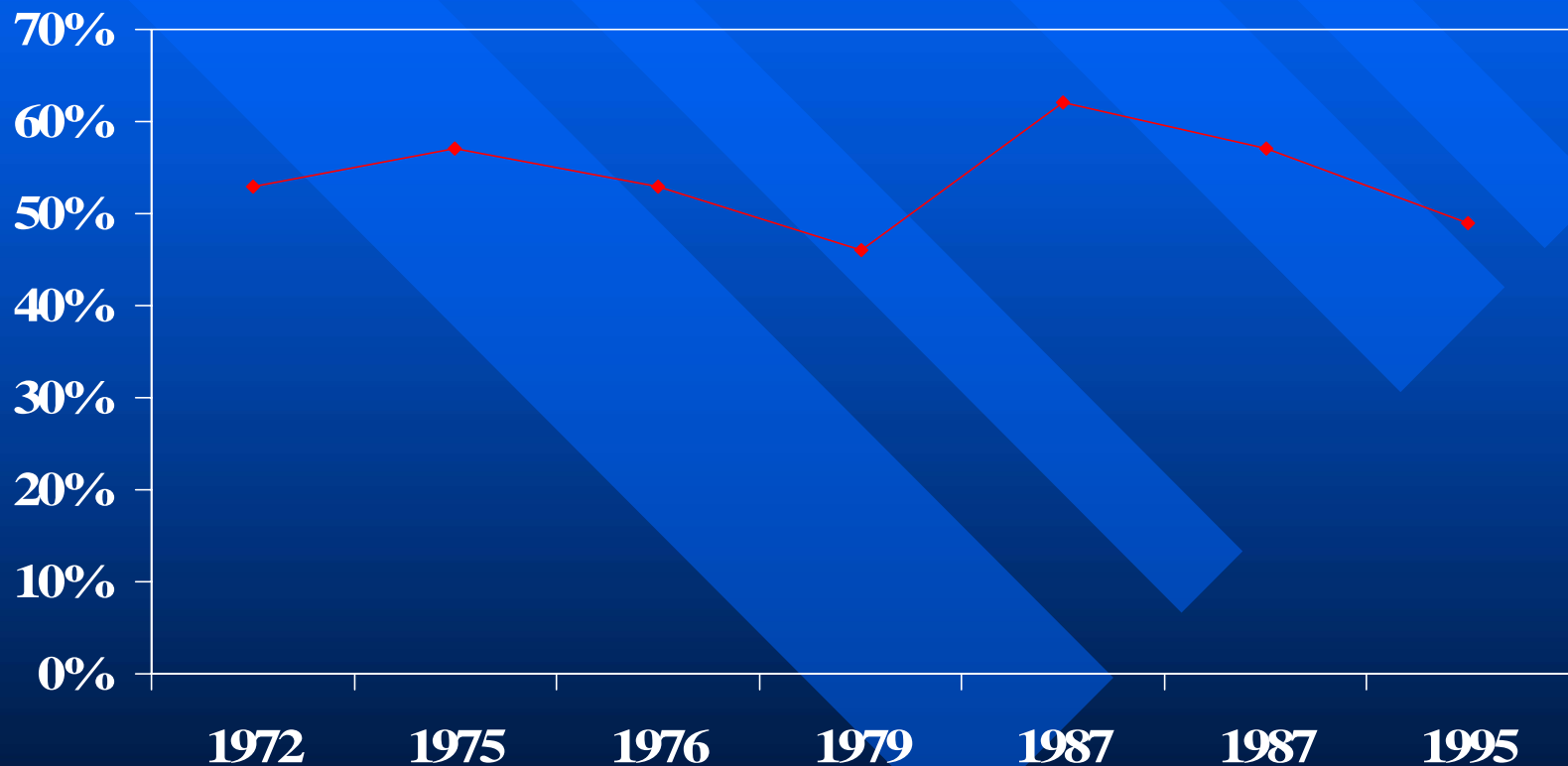
- Sample size: 269
- Average length of follow-up: 35 years
- Rates of significant improvement or recovery for schizophrenia:
✓ 49%

DeSisto, M., Harding, C.M., Ashikaga, T., McCormick, R., & Brooks, G.W. (1995). The Maine and Vermont three-decade studies of serious mental illness: Matched comparison of cross-sectional outcome. British Journal of Psychiatry, 167, 338-342.

DeSisto, M., Harding, C.M., Ashikaga, T., McCormick, R., & Brooks, G.W. (1995). The Maine and Vermont three decade studies of serious mental illness: II. Longitudinal course comparisons. British Journal of Psychiatry, 167, 338-342.

(From Deegan' Lessons in Recovery and Resilience)

Longitudinal Studies: Recovery Rates



(From Deegan' Lessons in Recovery and Resilience)

Assumptions about Recovery

- Recovery is highly individualized
- Recovery can occur with recurrent symptoms
- Recovery from Stigma if mental illness is sometimes more difficult than recovering from illness itself

■ Adapted from Anthony, Deegan and others

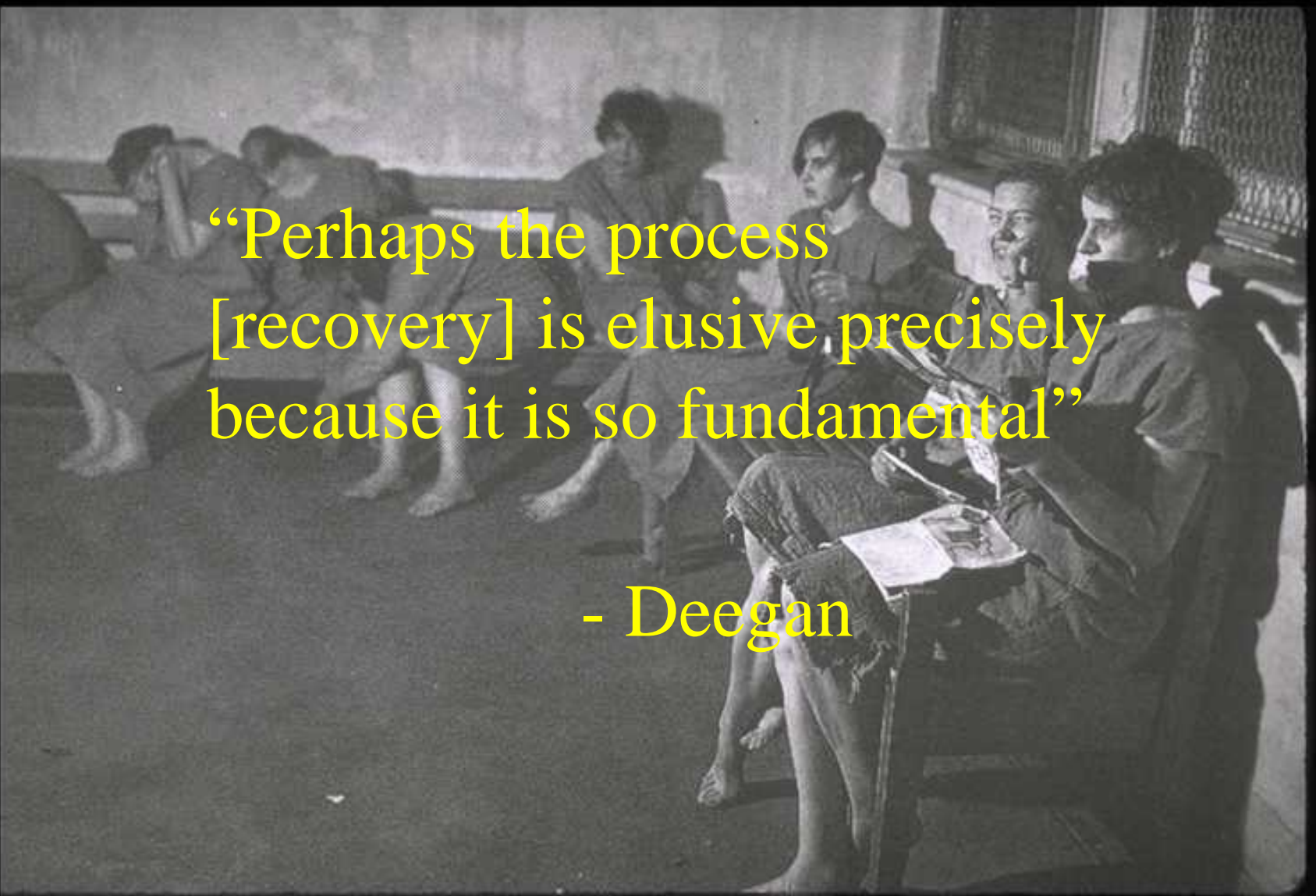
Assumptions about Recovery

- Recovery is not the same as cure
- Recovery is having more to life than illness
- Recovery is a process, not a destination
- Recovery is both done and defined by the person

■ Adapted from Anthony, Deegan and others

Recovery

- Rehabilitation is what professionals do
- Recovery is what consumers experience
 - The person's own experience is in the center of recovery

A black and white photograph showing a group of young people, possibly students, sitting on the floor in a room. They are dressed in casual clothing like t-shirts and jeans. Some are looking at books or papers, while others are looking towards the camera. The room has a simple, somewhat institutional feel with a plain wall and a window with a metal grille in the background.

“Perhaps the process
[recovery] is elusive precisely
because it is so fundamental”

- Deegan

DSM-IV-TR (2000)

- “... an accurate summary of the long-term outcome of Schizophrenia is not possible. Complete remission (i.e., a return to full premorbid functioning) is probably not common in this disorder. Of those who remain ill, some appear to have a relatively stable course, whereas others show a progressive worsening associated with severe disability.”

DSM-III (1980)

- “The most common course [of schizophrenia] is one of acute exacerbations with increasing residual impairment between episodes.”

“Dramatic improvement in a patient with a diagnosis of schizophrenia was regarded by many clinicians as evidence of original misdiagnosis”

- Rund, BR; Fully Recovered Schizophrenics: a retrospective study of some premorbid and treatment factors. *Psychiatry* 1990; 53:127-139

Biological Psychiatry

- “Relatively little attention has been paid to the role of neuro-degenerative processes [in Schizophrenia] despite the clinical course of the illness and the fact that most patients experience varying degrees of behavioral and cognitive deterioration.”
 - J. Lieberman, Biological Psychiatry (1999)

Kaplan and Sadock's Comprehensive Textbook of Psychiatry, 7th edition (2000)

- “Studies in Europe, the United States, Japan that followed up persons who experienced disabling forms of schizophrenia during adulthood found, 20 to 40 years later, a remarkable 50 to 66 percent functioning actively in their communities with few symptoms, a reasonably good subjective quality of life, and only limited dependence on professional caregivers.” (R. Liberman)

Kaplan and Sadock's Comprehensive Textbook of Psychiatry, 7th edition (2000)

- “These findings have spurred interest in psychiatric rehabilitation as a way to facilitate social and symptomatic **recovery** of seriously mentally ill persons.”

•(R. Liberman)

Remission in Schizophrenia: Proposed Criteria and Rational for consensus

- American Journal of Psychiatry, March 2005
- Nancy C. Andreasen, M.D., Ph.D., et al
- Remission in Schizophrenia Working Group
- “To Develop a Consensus Definition of Remission as applied to Schizophrenia”

Remission in Schizophrenia: Proposed Criteria and Rationale for consensus

- “The need for such a definition is timely because...evidence that traditional predictions of generally poor outcome may have been overstated.”

■ Nancy C. Andreasen, M.D., Ph.D., et al
Am J Psychiatry 2005; 162:441-449

Myths about Schizophrenia

- Inevitable downhill course of illness
- Rehabilitation useful only after stabilization
- Medications needed forever
- People with MI can only work at low-level jobs



The President's New Freedom Commission on Mental Health

Achieving the Promise:

Transforming Mental Health Care in
America

President's New Freedom Commission on Mental Health

Achieving the Goal: Recommendation 2.2

Involve consumers and families fully in orienting the mental health system toward recovery

Vision Statement:

“We envision a future when everyone with a mental illness will recover...”

The term “Recovery” has led to Confusion/Conflict

- Consumers

- Who are expected to recover

- Professionals and Policy Makers

- Who are expected to help them

The Top Ten Concerns About Recovery Encountered in Mental Health System Transformation

- Recovery is old news. “What is all the hype? We’ve been doing recovery for decades”
- Recovery-oriented care adds to the burden of mental health professionals who already are stretched thin by demands that exceed their resources.
- Recovery means that the person is cured. (When clearly the person is still very disabled.)

The Top Ten Concerns (Continued)

- Recovery happens for very few people with serious mental illness
- Recovery in mental illness is an irresponsible fad
- Recovery happens after, and as a result of, active treatment and the cultivation of insight
- Recovery can be implemented only through the introduction of new services

■ Davidson et al.; Psychiatric Services May 2006

The Top Ten Concerns (Continued)

- Recovery-oriented services are neither reimbursable nor evidence based
- Recovery approaches devalue the role of professional intervention.
- Recovery increases providers exposure to risk and liability.

■ Davidson et al.; Psychiatric Services May 2006

The Top Ten Concerns (Continued)

- “Once it is firmly established, the recovery vision will allow us to see, albeit in retrospect, that the costs incurred by not taking such risks – the costs of chronicity, institutionalization, and homelessness – far outweigh the cost of doing so.”

■ Davidson et al.; Psychiatric Services May 2006

What is Recovery?

A Conceptual Model

Jacobson and Greenley; Pscych Services; April 2001

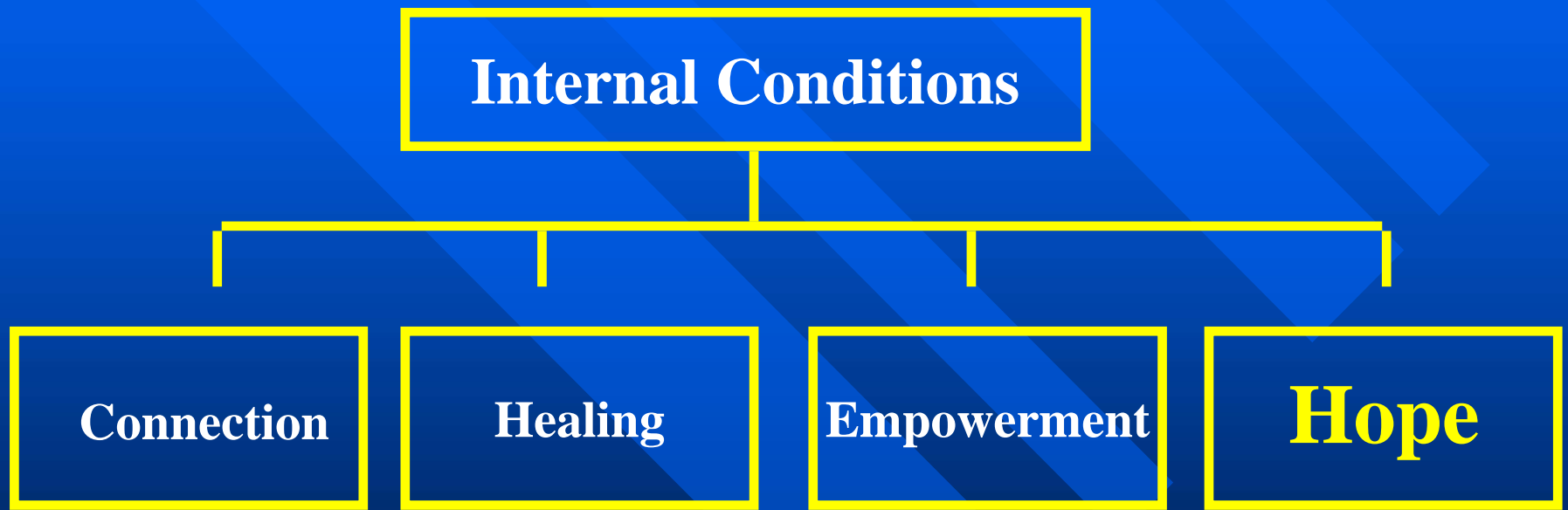
■ Internal Conditions

- Attitudes, experiences and processes of change of individuals who are recovering
 - » Hope
 - » Healing
 - » Empowerment
 - » Connection

■ External Conditions

- Circumstances, events, policies and practices that may facilitate recovery
 - » Human Rights
 - » A positive culture of healing
 - » Recovery-oriented services

Recovery



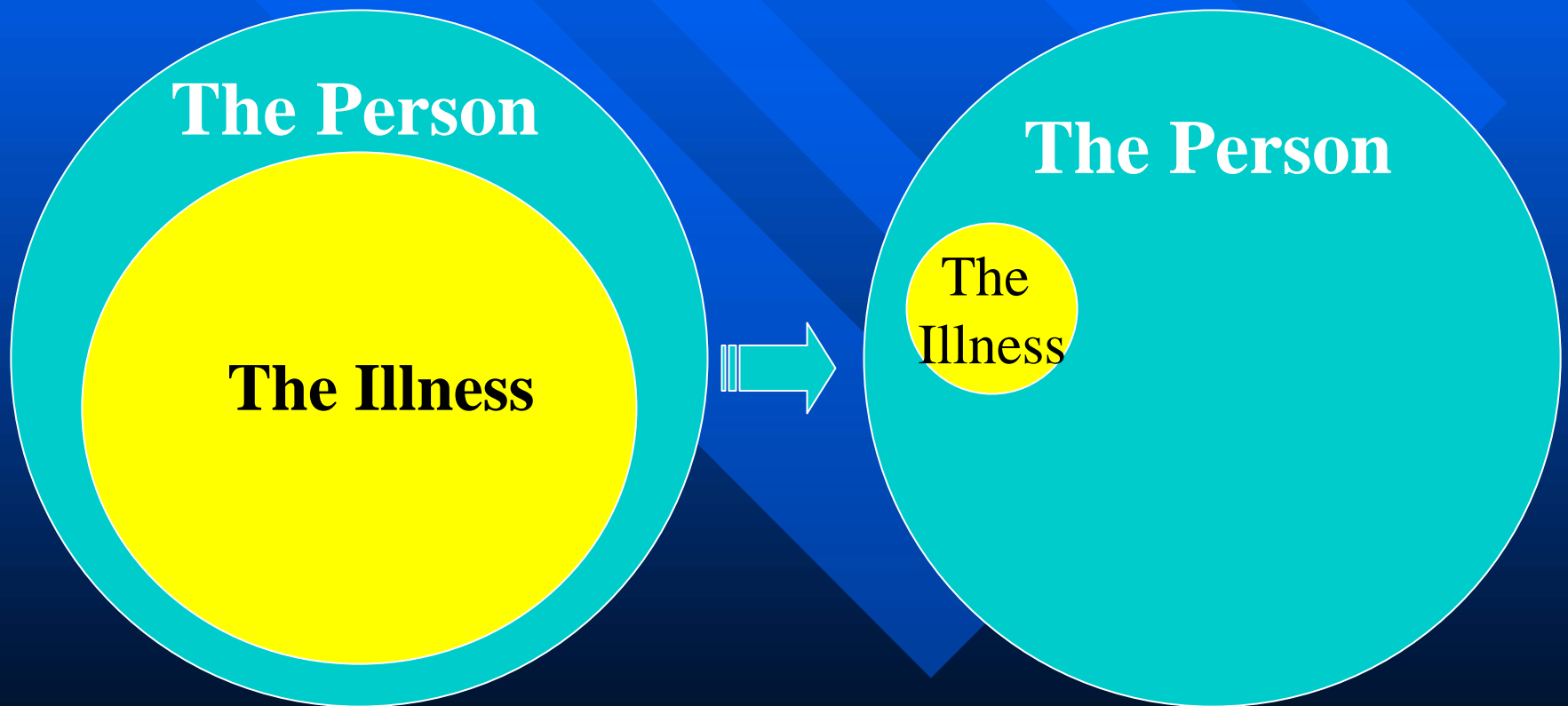
Jacobson: N, A Conceptual Model of Recovery

- **Connection:** rejoining the social world or “getting a life”
- Recovery is a profoundly social process
- For many, this means helping others who are also living with mental illness
 - Becoming provider
 - Peer support
 - Advocate
 - Telling personal story

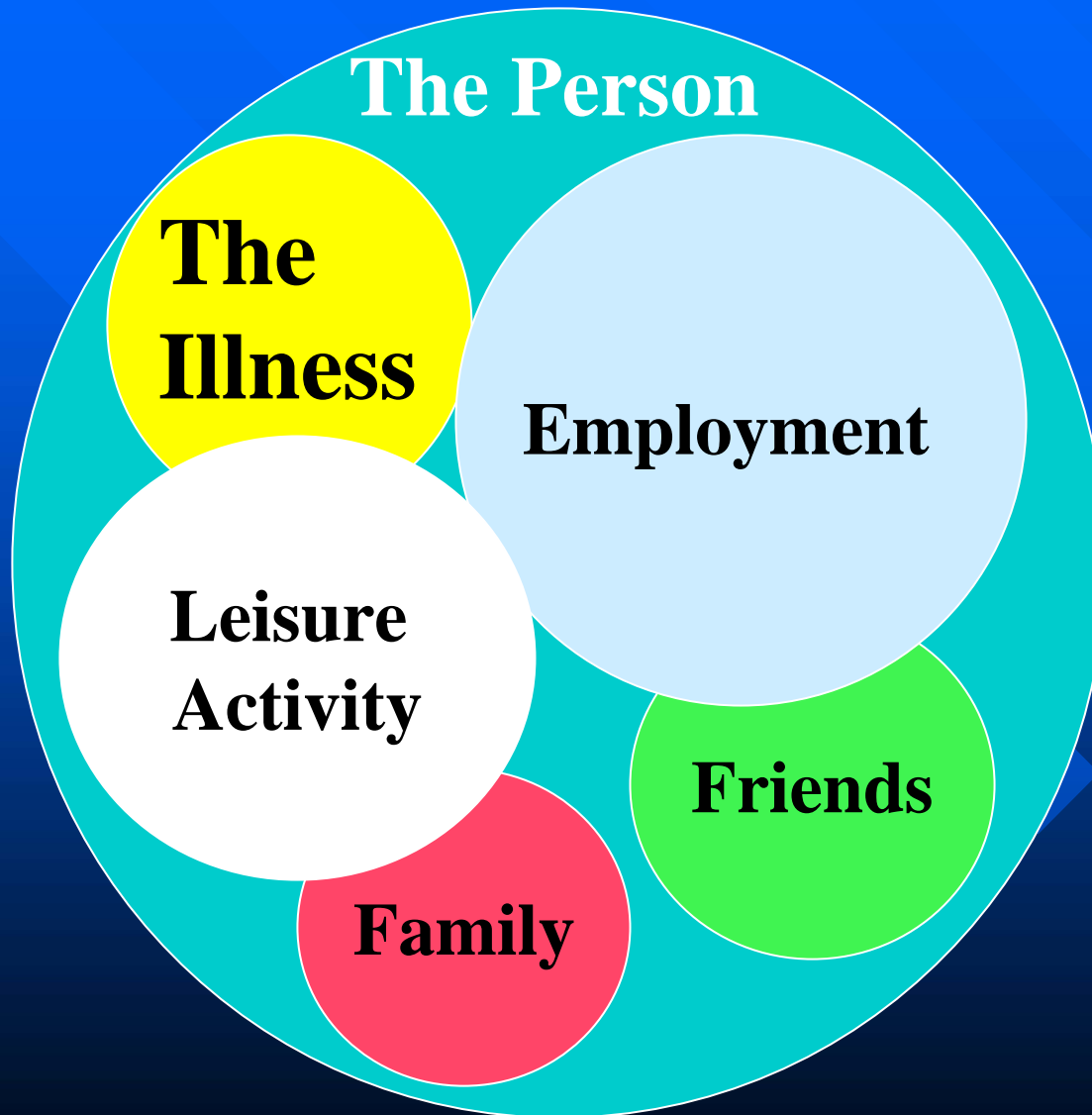
■ Healing

- Recovery is NOT synonymous with ‘cure’
- Recovery concept is not necessarily a return to “normal”
- Two components of Healing in Recovery:
 - » Defining the self apart from illness
 - » Control

Process of Recovery



Process of Recovery



I've finally decided,
With some inner will, -
That I'm too busy,
To be mentally ill,
I take my meds,
And try to think,
Sitting and talking,
With the shrink,
I am so busy,
I don't have time,
To think about it,
All the time.
I'm so busy,
Be assured,
I won't even noticed,
If I am cured.

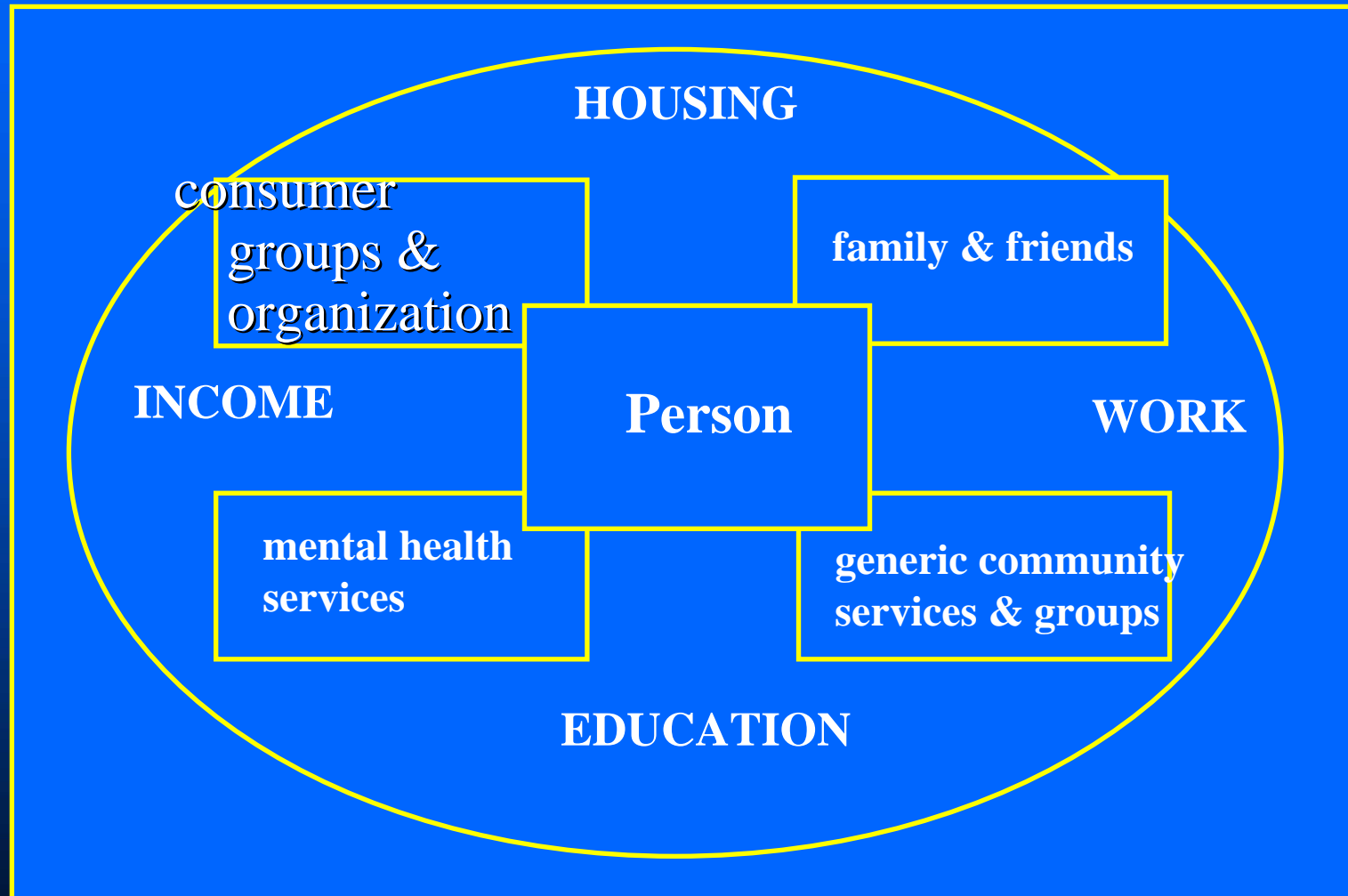
- Dylan Abraham

- **Empowerment:** a corrective for the lack of control and dependency that many consumers develop after long-term interactions with the mental health system
- 3 Components
 - Autonomy
 - » Knowledge
 - » Self-confidence
 - » Availability of meaningful choices
 - Courage
 - » Willingness to take risks
 - » To speak in one's own voice
 - » To step out of safe routines
 - Responsibility

Traditional Approach Swaddles Patients with Services



Recovery Oriented System Supports But Does Not Surround Consumer



– **Hope**: the individual's belief that recovery is possible

– Attitudinal components of **Hope** are:

- » Recognizing, accepting that there is a problem
- » Committing to change
- » Focusing on strengths rather than on weakness or possibility of failure
- » Looking forward rather than ruminating on past
- » Celebrating small victories
- » Reordering priorities
- » Cultivating optimism

(Jacobson and Greeley)

Models of Recovery



Jacobson: N, A Conceptual Model of Recovery

External Conditions of Recovery

■ Human Rights

- Reducing/eliminating stigma
- Protecting rights of persons in service system
- Providing equal opportunities (education, housing, employment)

■ A Positive Culture of Healing

- Tolerance, listening, empathy, compassion, respect, safety, trust

■ Recovery Oriented Services

- Attitude of the professionals who provide them
- Partnership, collaboration

You and I

By Laurie Curtis

Adapted from a poem also entitled You and I by Elaine Popovicti

I am a resident You reside. I am placed. You move in.

I am learning daily living skills. You hate housework. You use a cleaning service, a laundry service and have take-out pizza for dinner.

I get monitored for tooth-brushing. You never floss.

I have to be engaged in a meaningful activity everyday. You take mental health days, holidays and go on vacation.

You and I

By Laurie Curtis

Adapted from a poem also entitled You and I by Elaine Popovitch

I am aggressive. You are assertive. I am aggressive. You are angry.

I am depressed. You are sad. I am depressed. You grieve. I am depressed. You feel stressed and overwhelmed.

I am manic. You are excited. I am manic. You feel passionate and energized. I am manic. You charge to the limit on your credit card.

I am non-compliant. You don't like being told what to do.

I am treatment resistant because I stop taking medication when I feel better. You never complete a 10 day course of antibiotics.

I am in denial. You don't agree with how others define your experience.

I am manipulative. You act strategically to get your needs met.

You and I

By Laurie Curtis

Adapted from a poem also entitled You and I by Elaine Popovicti

My case manager, therapist, nurse, doctor, rehabilitation counselor, residential counselor and vocational counselor all set goals for me for next year. You haven't decided what you want out of life.

I am a consumer, a patient, a client, a survivor, a schizophrenic, a bipolar, a borderline. You are a whole person — complete with your gifts, strengths, weaknesses and challenges in living.

Someday I will be discharged...maybe. You will move onward and upward, perhaps even out of the mental health system. You see, I have problems called chronic; people around me have given up hope. You are in a recovery process and get support to take it one day at a time.

The Disease Centered Model

■ Professional Role

- Hierarchical
- Paternal
- In-charge
- Holds the important knowledge
- Responsible for treatment
- Disease is focus

■ Patient's Role

- Subservient
- Obedient
- Passive
- Recipient of knowledge
- Responsible for following treatment
- Host of the disease

Recovery: Person Centered Model

■ Person's Role

- Personal power
- Personal knowledge
- Personal responsibility
- Person in context of life is the focus
- Person is self-determining

■ Professional Role

- Power sharing
- Exchange information
- Shared decision-making
- Co-investigator
- Professional is expert consultant on journey

Practical Examples of the Recovery Vision:

- Revision of FRP process
- Seclusion and Restraint reduction
- Policy changes on Pass/leave
- LOS reduction
- TOVA vs Mandt training

TOVA vs Mandt training/interventions



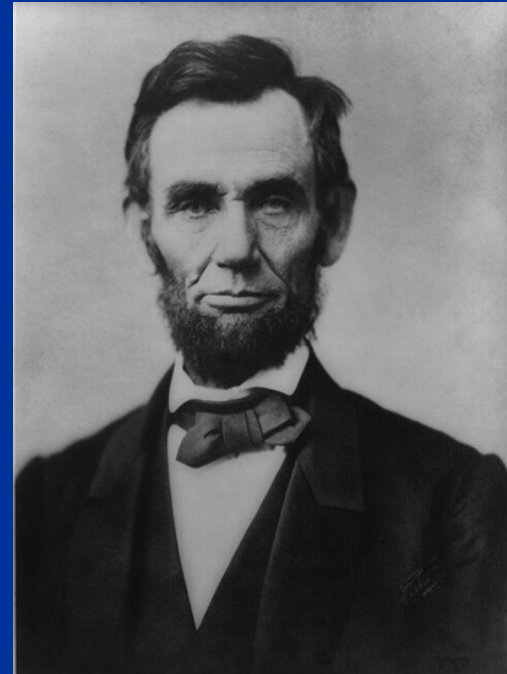
**“Violence is the
language of
the unheard”**

-- Martin Luther King, Jr.

TOVA vs Mandt training/interventions

“Nearly all men can stand adversity, but if you want to test a man’s character, give him power.”

-- Abraham Lincoln



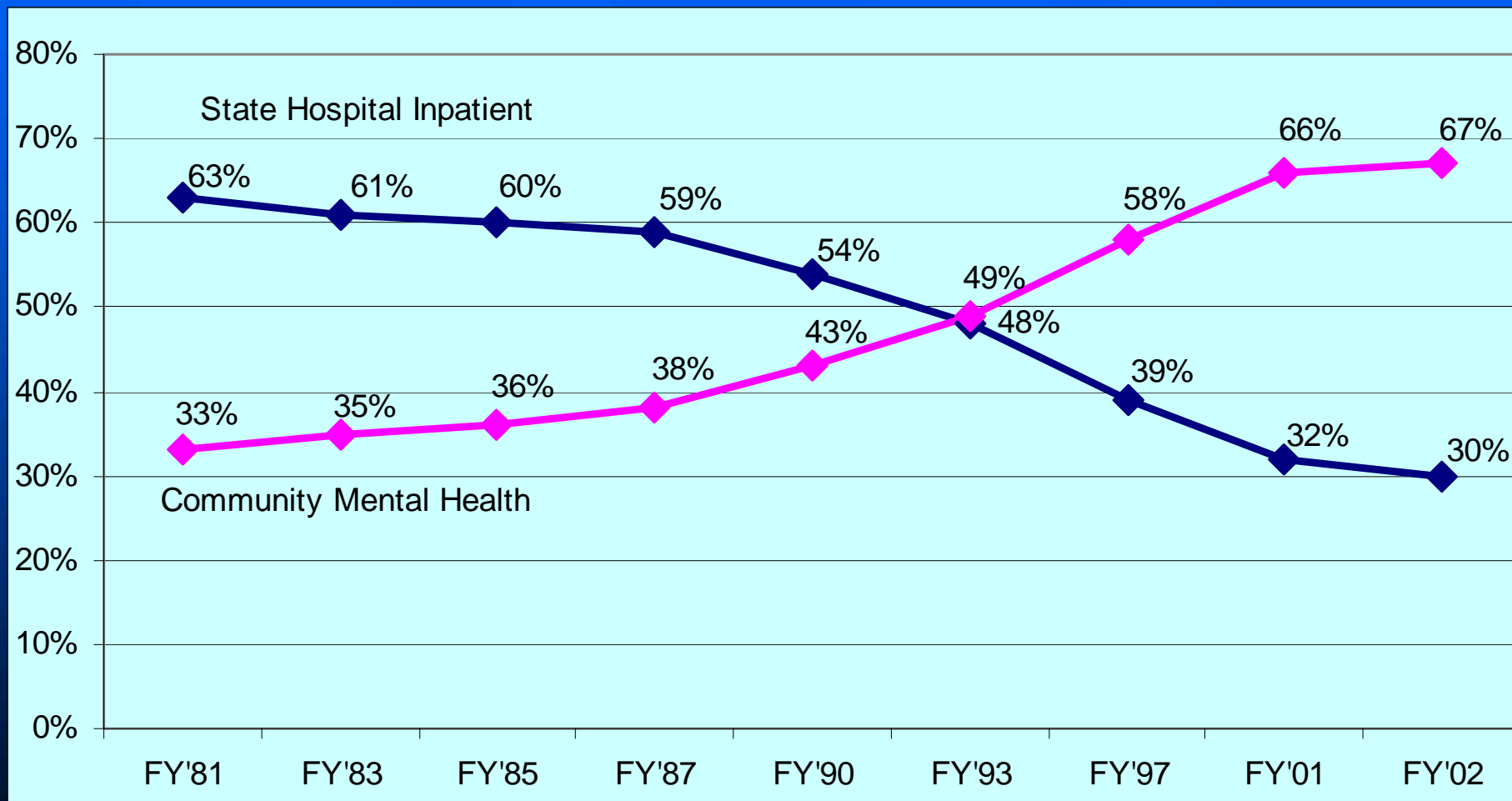
Practical Examples of the Recovery Vision:

- Crisis Stabilization and other community alternative capacity enhancements vs increasing “traditional” inpatient beds
- Crisis Intervention Teams (CIT)
- Mental Health Courts
- Increased involvement of consumers as providers of care

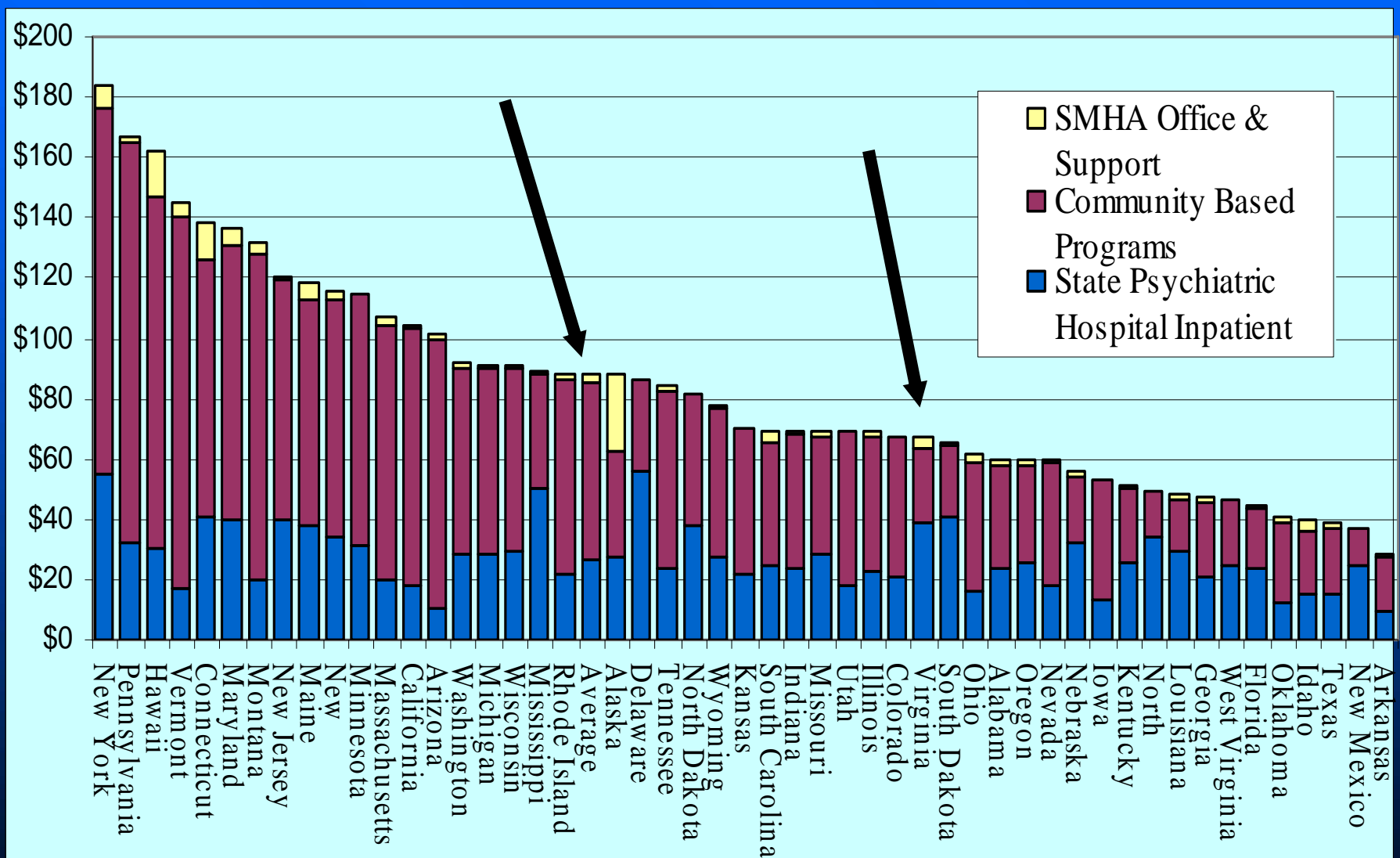
System Transformation Initiative

- Over the next biennium the System Transformation Initiative will:
 - **Provide total community investment of \$194.61 million**
 - **Rebuild four state facilities, creating smaller, more efficient state-of-art psychiatric hospitals and training centers for people with mental retardation:**
 - » Eastern State Hospital (ESH) – Replace facility (\$ 59.72 million)
 - » Western State Hospital (WSH) – Planning funds (\$ 2.5 million)
 - » Central Virginia Training Center (CVTC) – Planning funds (\$ 2.5 million)
 - » Southeastern Virginia Training Center (SEVTC) – Planning funds (\$ 2.5 million)

State Mental Health Agency Controlled Expenditures for State Psychiatric Hospital Inpatient and Community-Based Services as a Percent of Total Expenditures: FY'81 to FY'02



FY'02 Per Capita SMHA-Controlled Expenditures for Mental Health



Consumer identification of what helped in their own recovery

- Generally health professionals not helpful
- But almost all participants able to identify at least one health professional who was very helpful
- More like the relationship one has with a friend

Factors Identified By Consumers As Most Important To Their Recovery

- Determination
- Illness Management
- Self-Help
- Having Friends Who Accepted Them
- The Negative Effects Of Medication
- The Negative Effects Of Health Professionals
- Accepting The Illness
- Crisis Response As Part Of The Process
- Struggling With Their Ability To Recover

Tooth, Kalyansundaram and Glover
Recovery from Schizophrenia: A consumer perspective
1998

Meds Alone Couldn't Bring Robert Back February 6, 2006

Experts like to debate the effectiveness of new drugs, but they overlook a key element of recovery.

What had made the difference?

Some pointed to new medications, some to old; some said they had found God; some attributed their transformation to a particular program, but no matter what else they named, they **all—every last one—said that a key element was a relationship with a human being.** Most of the time, this human being was a professional—a social worker, a nurse, a doctor. Sometimes it was a clergyman or family member.

In every instance, though, it was the presence in their lives of an individual who said, in effect, "I believe in your ability to recover, and I am going to stay with you until you do" that brought them back. So it was with my brother, who, through his daily collaboration with Alan and the dedication of Dr. Pam (who refused to go along with the staff consensus that Robert would never live on his own) has not had a single recurrence for more than six years, the longest stretch in his adult life.



Power to Heal: Due to the dedication of Dr. Pam, my brother has not had a recurrence for more than six years